

# **Best interests decision- making for adults who lack capacity**

A toolkit for doctors  
working in England  
and Wales



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If you have any comments on this toolkit, please address them to:

### **Medical Ethics and Human Rights Department**

British Medical Association  
BMA House  
Tavistock Square  
London  
WC1H 9JP

Email: [ethics@bma.org.uk](mailto:ethics@bma.org.uk)

Website: [www.bma.org.uk/ethics](http://www.bma.org.uk/ethics)

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## About this toolkit

Decisions for adults who lack the capacity to consent to medical treatment in England and Wales are governed by the Mental Capacity Act 2005 (MCA). The MCA specifies that, any act done, or decision made, for a person who lacks capacity must be made in their best interests.

The MCA does not define best interests. Instead, it sets out a process to be followed when making a decision. In most circumstances it will be clear where the individual's best interests lie, and a decision as to care or treatment will not be challenging or time-consuming – but this is not always the case. Whether to provide analgesics for someone in pain is likely to be a straightforward question; a decision about whether to continue providing life-sustaining treatment is less so.

This toolkit provides practical guidance to help doctors make decisions in the best interests of adults who lack capacity. It sets out the decision-making process that should be followed, the different factors to consider, and how these should be balanced. It also signposts to further reading and sources of support. Although aimed primarily at doctors, much of the information here will be useful to other members of the healthcare team involved in treating and caring for patients who lack capacity. As members of the multi-disciplinary team (MDT), they will have a crucial role in best interests assessments and decisions.

This toolkit applies to England and Wales only. In Scotland, decision-making in this area is covered by the Adults with Incapacity (Scotland) Act 2000. In Northern Ireland, it is governed by the common law (although at the time of writing, change is anticipated). Although many of the basic principles outlined in this guidance will be applicable, doctors working in Scotland and Northern Ireland should not rely on this toolkit without also referring to country-specific guidance.

Although the MCA governs decision-making for people aged 16 and over, there are additional considerations for decision-making involving young people aged 16 to 18. For this reason, you should consult additional guidance for decisions involving a young person between the ages of 16 and 18, such as our Children and Young People Toolkit.

This toolkit does not provide a set of rules or instructions which should be followed without reflection. It is a tool to inform and aid decision-making. When facing particularly challenging ethical or legal dilemmas in relation to best interests decision-making, further advice can be sought from the BMA, the GMC or your medical defence organisation.

This toolkit only applies in circumstances where it has already been established that an adult lacks capacity and cannot consent to or refuse treatment themselves. If you are looking for more general information about the assessment of capacity or consent, or about decision-making for children and young people, you should refer to our other content-specific toolkits:

- Mental Capacity Act Toolkit
- Consent and Refusal Toolkit
- Children and Young People Toolkit
- Adult Safeguarding Toolkit

All of these are available to download from [www.bma.org.uk/ethics](http://www.bma.org.uk/ethics)



## Section 1: The Mental Capacity Act 2005: a refresher

The Mental Capacity Act 2005 (MCA) provides a legal framework in England and Wales for decision-making on behalf of people aged 16 or over who cannot make decisions for themselves. It applies to all decisions taken on behalf of people who lack capacity, whether permanently or temporarily. All doctors who work with adults who lack, or who may lack capacity, need to be familiar with the Act and its principles and provisions. You can find more in-depth information about the Act in our separate toolkit on the Mental Capacity Act 2005, which is available to download from [www.bma.org.uk/ethics](http://www.bma.org.uk/ethics).

It is important to remember that capacity is decision-specific: it focuses on the specific decision that needs to be made at the time that decision is required. It is not a single, one-off event, but one that must be regularly assessed in relation to each decision required.

In all decisions, you should observe the following **five statutory principles** as set out in the MCA:<sup>1</sup>

The first three principles are directed at the first stage of decision-making under the MCA, which involves establishing whether someone has the capacity to make a certain decision. For more information on how these are to be applied in practice, please see the BMA's Mental Capacity Act Toolkit.

The final two principles kick in if it is established that a person lacks the capacity to make the decision required, and decision-making must proceed on the basis of best interests. It is these final two principles which are most important in the context of this toolkit.

1. **Presume capacity:** a person must be assumed to have capacity unless it is established that he or she lacks capacity. The responsibility for proving that someone lacks capacity falls upon the person challenging it.
2. **Provide support:** a person is not to be treated as unable to make a decision unless all practicable steps have been taken to support him or her to do so – e.g. involving advocates or communication support (such as someone who knows the person well and can assist with communication, or a speech and language therapist); taking steps to address whether an individual's capacity is affected by the time of day or medication regimes.
3. **Unwise decisions:** a person is not to be treated as unable to make a decision merely because he or she makes a decision that you think is unwise or irrational.
4. **Best interests:** any act done or decision made for, or on behalf of, a person who lacks capacity must be done or made in his or her best interests.
5. **The less restrictive option:** before the act is done, or the decision is made, regard must be had as to whether the purpose can be effectively achieved in a way that is less restrictive of the person's rights and freedoms.

1 Mental Capacity Act 2005 s.1(1)-1(6).

# 2

## Section 2: Decision-making for people who lack capacity

### Key points:

The Mental Capacity Act (MCA) provides various ways in which decisions can be taken for, or in relation to, people who lack capacity:

- Where a person has made a valid and applicable advance decision to refuse treatment (ADRT) which applies in the person’s clinical situation, the ADRT must be respected. Here, there is no best interests decision to be made, as the person has already made the decision in advance.
- Where a person has made a lasting power of attorney (LPA) appointing a health and welfare attorney with the relevant powers (including, in the context of decisions about life-sustaining treatment, the power to consent to or refuse treatment), the attorney is the lawful decision-maker. They must act in the person’s best interests.
- In some cases, the Court can appoint a deputy to make decisions for people who lack capacity. In these cases, the deputy is the decision-maker.
- In some cases, either the decision required or the circumstances in which it is being made, will mean that the Court of Protection should be asked to decide.
- In all other cases, decisions should be made following the clinician-led best interests process.

### Is a best interests decision required?

Once it has been judged that someone lacks the capacity to make a decision, the first question to establish is whether a best interests decision is required. The MCA provides various ways in which decisions can be taken for or in relation to people who lack capacity.

For more information on these approaches to decision-making for people who lack capacity, please see our separate Mental Capacity Act toolkit, available at [www.bma.org.uk/ethics](http://www.bma.org.uk/ethics).

### 1. Advance decisions to refuse treatment (ADRTs)

Sometimes a person will have made a valid and applicable advance decision to refuse treatment (ADRT), which applies in the person’s clinical situation. Here the person has already decided to decline a certain treatment and that decision must be respected, as if it were a person with capacity making it.

Although ADRTs can be made orally or in writing, an advanced refusal will only apply to life-sustaining treatment when it is in writing, is signed and witnessed, and contains a statement that it is to apply even where life is at risk.<sup>2</sup> You should give these ADRTs the “utmost care, attention and scrutiny” and make sure you ask to see a copy of the ADRT, rather than relying on a summary of it.<sup>3</sup>

It should be assumed that the person had capacity at the time they made the ADRT. If there is any doubt as to this, or about its validity or applicability, legal advice should be sought and, if necessary, the Court of Protection may be asked whether the ADRT can be relied upon.

<sup>2</sup> Mental Capacity Act Code of Practice s.9.10; ss.9.24-9.28.

<sup>3</sup> *NHS Cumbria CCG v Mrs Jillian Rushton* [2018] EWCOP 41.

# 2

## 2. Lasting power of attorney (LPA)

Some people have made a lasting power of attorney (LPA) appointing a health and welfare attorney. Where this person has the appropriate powers (including, in the context of decisions about life-sustaining treatment, the power to consent to or refuse such treatment), and the LPA has been registered with the Office of the Public Guardian (OPG), the health and welfare attorney is the lawful decision-maker.

They must, however, follow the principles of the MCA – including fulfilling the duty to consult with others – and can only act in the person’s best interests. If there is genuine doubt or uncertainty that the attorney is acting in the best interests of the person, this should be resolved as soon as possible. If you have concerns about an attorney, you should contact the OPG. If doubt or disagreement persists, the Court of Protection should be involved.

It is important that you ask to see the original LPA document (embossed with “validated – OPG” at the bottom of each page) and check that it does indeed confer the appropriate powers required for the decision.

Attorneys cannot be compelled to make a decision. In some circumstances, they may feel unable to draw a clear picture of what would be in the person’s best interests, or unable to make the decision required. If an attorney chooses to exempt themselves from the decision-making process, responsibility will fall to the relevant clinician to carry out a best interests assessment.

## 3. Court-appointed deputies

In some cases, the Court of Protection may have appointed a deputy to make welfare and healthcare decisions for someone who lacks capacity.<sup>4</sup> The decision to appoint (and who to appoint) is to be taken in the best interests of the person, taking into account their wishes and feelings, and also the principle that the appointment of a deputy is not necessarily less restrictive of a person’s rights and freedoms than the normal decision-making process of the MCA.<sup>5</sup>

Where there is a court-appointed deputy, they are the decision-maker. They can only make those decisions that they are authorised to make by the order of the court, and they cannot consent to or refuse life-sustaining treatment.<sup>6</sup>

It is important that you see the official documentation appointing the deputy and check the powers that have been conferred on them.

The deputy must follow the principles of the MCA and act in the person’s best interests. The OPG is responsible for supervising deputies appointed by the Court of Protection and making sure they carry out their tasks in line with the MCA. They can also investigate and take action if there are concerns or reports of abuse regarding a deputy, or where a deputy is not performing their required duties.

<sup>4</sup> Mental Capacity Act 2005 s.16.

<sup>5</sup> *Re Lawson, Mottram and Hopton (appointment of personal welfare deputies)* [2019] EWCOP 22.

<sup>6</sup> Mental Capacity Act 2005 s.20(5).





#### 4. Court of Protection

The MCA established the Court of Protection to make a decision or to appoint a decision-maker on someone's behalf in cases where there is no other way of resolving a matter affecting a person who lacks capacity.

This may arise because there is disagreement – whether within the clinical team, within a family, or between the clinical team and those close to the patient – about what is in the best interests of a person. Depending on the nature of the disagreement, further discussion, a second opinion, or the involvement of a clinical ethics committee (CEC) or medical mediation services may help resolve the issue. If these options fail to resolve the issue, legal advice should be sought to decide whether an application to the Court of Protection is required.

There may be other cases where the Court of Protection should be asked to decide – either because the decision being made is sufficiently serious, or because of the circumstances of a particular case.

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#### Cases where the Court of Protection should be involved:

- In any case where, following the conclusion of the medical decision-making process, there remains doubt or disagreement as to the proposed course of action, or where the decision is “finely balanced”.<sup>7</sup>
- In any case involving the potential for a serious interference with a person's rights, for example:
  - where a medical procedure or treatment is for the primary purpose of sterilisation;
  - in cases involving organ, bone marrow, or stem cell donation from a person who lacks capacity;
  - procedures for the covert insertion of a contraceptive device or other means of contraception;
  - where it is proposed that an experimental or innovative treatment be carried out;
  - any case involving a significant ethical dilemma in an untested or controversial area of medicine.
- Separately, an application to the court may be required where the proposed procedure or treatment is to be carried out using a degree of force or restraint which exceeds that set out in sections 5 and 6 of the MCA. For further guidance on how to proceed in these cases, please see our separate guidance on deprivation of liberty safeguards (DoLs).

This is not an exhaustive list, and you should seek legal advice as to when an application to the Court of Protection will be necessary.

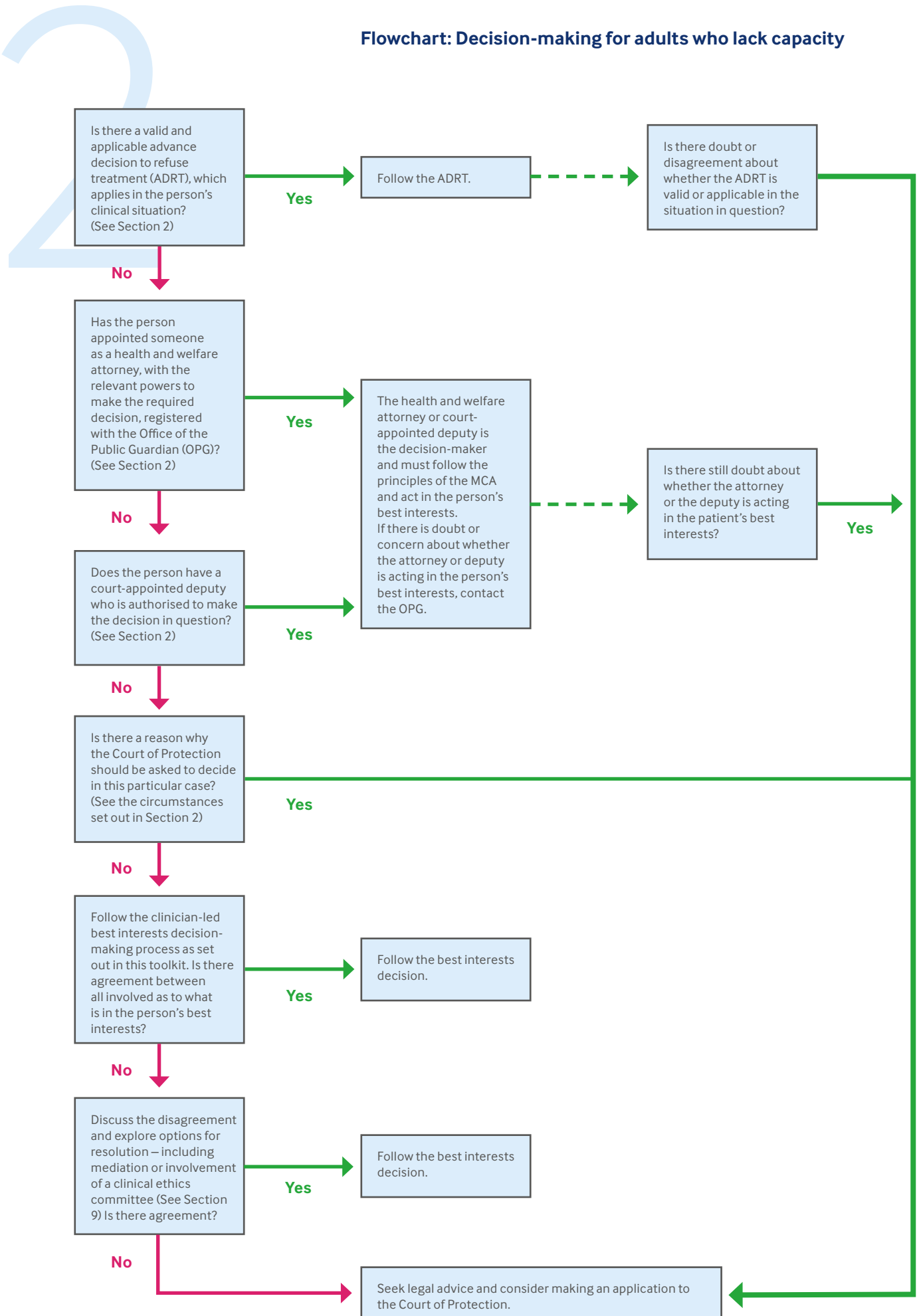
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In all cases where the Court of Protection is involved, applications should be made promptly so as to avoid unnecessary delays in reaching a decision as to what is in a person's best interests.

#### 5. Clinician-led best interests decision-making

In all other cases, decisions must be made by the clinical team on the patient's behalf, based on his or her best interests. The remainder of this toolkit sets out the process to be followed, and the factors to be taken into consideration.

**Flowchart: Decision-making for adults who lack capacity**



# 3

## Section 3: Key principles of best interests decision-making

### Key points:

- There is no single definition of best interests. Instead, the Mental Capacity Act 2005 (MCA) sets out a checklist of factors to be considered when making a best interests decision.
- Best interests are not just medical best interests. You must consider the person's welfare in the widest possible sense, and consider the individual's broader wishes and feelings, and values and beliefs.
- All decisions should follow careful consideration of the individual circumstances of the person and focus on reaching the decision that is right for that person – not what is best for those around them, or what the "reasonable person" would want.
- Wherever possible, the person who lacks capacity to make a decision should still be involved in the decision-making process. You should take all reasonable steps to permit and encourage the person to participate or to improve their ability to participate in the decision.
- You must take account of the person's past and present wishes, feelings, values and beliefs where those are known or can be reasonably ascertained.
- Those involved in caring for the person, or interested in his or her welfare, must be consulted about their views on the person's best interests, and the person's past and present wishes, feelings, beliefs and values.
- What will be required of a best interests assessment process will depend upon what is reasonable, practical, and appropriate in each case.
- It is not just the decision reached which determines whether doctors have protection from liability, but also whether the correct process is followed.

### What is the decision required?

It is important to identify what decision needs to be made on the person's behalf. Not only is it important to be clear about what is needed, but it will also help guide how the best interests assessment will be conducted.

In almost all cases, there will have been a clinical decision on the part of the doctor and the rest of the healthcare team as to what treatment and intervention options are available. The best interests decision required will address which of the available options should be provided for this particular person.

There may well be situations in which it is clear that what the person would want is not available. Doctors cannot be compelled to offer or provide treatment that they do not believe is clinically appropriate. The Supreme Court has made clear that a person lacking capacity cannot be in a better position than a person with capacity. If the option would not be available for the person even if they had capacity and were requesting it, there is no requirement that this be offered by way of a best interests decision.<sup>8</sup>

There may be a number of different options on the table, and it is important to clearly identify what these are. It can also be helpful to set out, in relation to each of the options, and supported by appropriate reasoning:

- the risks and benefits to the individual;
- the likelihood of those risks and benefits occurring; and
- their relative seriousness to the individual.

<sup>8</sup> *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67.

# 3

**Avoid discrimination:** You must avoid making assumptions about someone's best interests on the basis of their age, appearance, clinical condition, or some other aspect of their behaviour.

**Relevant circumstances:** You must try to identify all the things the person would take into account if they were able to make the decision themselves.

**Assess whether the person is likely to regain capacity:** If they will, can the decision wait until then? This should not be used as a reason to avoid making a potentially difficult or complex decision, but must be based on consideration of individual circumstances.

**Encourage patient participation:** Wherever possible, the person who lacks capacity should still be involved in the decision-making process. You must take all reasonable steps to permit and encourage the person to participate in the decision – including using all practical means to improve their ability to do so. See Section 4 for more information.

**Life-sustaining treatment:** If the decision involves life-sustaining treatment, you must not be motivated by the desire to bring about the person's death. For more information on what this means, see Section 10.

**Find out the person's views:** You must try to find out what the person's views and wishes on their situation might be. More information on how to do that, and what sorts of things you should take into consideration, can be found in Sections 4 and 5.

**Consult others:** If it is practical and appropriate to do so, you must consult other people to find out whether they have any information about the person's views or wishes. More information about these groups of people and how to involve them can be found in Section 4.

This will be helpful when it comes to assessing what will be in the best interests of the person and in particular, if a balance sheet approach needs to be adopted (see Section 6).

## What are “best interests”?

“Best interests” are not defined in the MCA. This was a deliberate decision by those drafting the Act. It would be impossible to specify in advance what would be in every individual's best interests, and such decisions will be taken by a range of professionals, in a variety of settings and circumstances.

The MCA sets out a checklist of factors which must be considered when making a best interests decision. This checklist is not a hierarchy, and no one principle is more important than the others. The basic legal principles are as follows:

## Mental Capacity Act 2005, section 4 – Best interests

**(1) In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of –**

- a. the person's age or appearance, or
- b. a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about what might be in his best interests.

**(2) The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.**

**(3) He must consider:**

- a. whether it is likely that the person will at some time have capacity in relation to the matter in question, and
- b. if it appears likely that he will, when that is likely to be.

**(4) He must, so far as is reasonably practicable, permit and encourage the person to participate or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.**

**(5) Where the determination relates to life-sustaining treatment he must not, in considering whether treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.**

**(6) He must consider, so far as is reasonably ascertainable:**

- a. the person's past and present wishes and feelings (and in particular, any relevant written statement made by him when he had capacity),
- b. the beliefs and values that would be likely to influence his decision if he had capacity, and
- c. the other factors that he would be likely to consider if he were able to do so.

**(7) He must take into account, if it is practicable and appropriate to consult them, the views of:**

- a. anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
- b. anyone engaged in caring for that person or interested in his welfare,
- c. any donee of a lasting power of attorney granted by the person, and
- d. any deputy appointed for the person by the court, as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).

# 3

The Supreme Court has made clear that best interests cover more than just medical interests. In *Aintree v James* the Court said that in considering best interests assessments decision-makers must:

*“look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be”.<sup>9</sup>*

Best interests decisions, therefore, are not just decisions about the best clinical outcome for the person. Other factors, including their beliefs, wishes, and values will have a significant impact on the decision. In some cases, a decision about what is in the best interests of a person may be different from, or even incompatible with, a decision based on the best clinical outcome alone.

The focus of a best interests decision is on what is in the best interests of the individual person – not on what is best for those who are close to them, what is most convenient for those caring for them, or on what most “reasonable people” would choose.

## Protection from liability

Section 5 of the MCA provides protection for doctors from liability in relation to the decisions they make. If anyone acts or makes a decision with the reasonable belief that what they are doing is in the best interests of the person who lacks capacity, then – provided they have followed the best interests checklist, as set out above – they will have complied with the Act.

It would be possible for two different people to apply the checklist and reach a different conclusion as to what is in a person’s best interests: as long as a decision-maker is able to show that it was reasonable for them to think that a person lacked capacity and that they were acting in the person’s best interests at the time they made their decision or took action, they would be protected from liability under section 5.

It is not just the decision reached that determines liability, but also the process through which that decision was made.<sup>10</sup> For this reason, doctors should follow the process set out in the MCA, as set out in this toolkit, and carefully record the decision made, how this was reached, and the reasons for it.

## A proportionate approach to decision-making

What will be required of a best interests assessment process will depend upon the nature and circumstances of the case.

The law is clear that the defence given to health and social care professionals providing care and treatment will be guided by the concepts of “reasonableness, practicability and appropriateness”.<sup>11</sup> What is reasonable, practical and appropriate will depend on:

- **The decision being made:** where a decision is likely to have grave consequences for a person – for example, where it involves a decision to stop, start or continue life-sustaining treatment – it will require greater consideration, wider consultation with those close to the patient, and

<sup>9</sup> *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67. 39.

<sup>10</sup> *Winspear v City Hospitals Sunderland NHS Foundation Trust* [2015] EWHC 3250 (QB). 24.

<sup>11</sup> *Commissioner of Police for the Metropolis v ZH* [2013] EWCA Civ 69. 40.

# 3

more detailed documented evidence about the decision reached and the reasons for it. On the other hand, there will be other occasions where the appropriate decision will be so transparent that exploring alternatives is unlikely to be meaningful or necessary – for example, a decision to provide analgesia to someone who is clearly in pain.

- **The circumstances in which it is being made:** what will be required to have a reasonable belief as to a person’s best interests in an emergency situation in an emergency department at 3am will be very different to what will be required in order to make a decision as to the long-term care options for an elderly person with multiple comorbidities. In the former, there is likely to be little time to go through a formal decision-making process and follow the MCA checklist. Even in an emergency, however, there may still be an opportunity to communicate with, and involve, the person or those close to them (**see Section 4**).<sup>12</sup>

In an emergency situation where there is doubt as to what is in a person’s best interests, and treatment is required urgently, immediately necessary treatment should always be provided – unless there is a valid and applicable advance decision refusing such treatment (ADRT). There is a strong presumption that it is a person’s best interests to receive life-sustaining treatment and the MCA will provide protection from liability for doctors who provide life-sustaining treatment in these circumstances – even if later evidence emerges, which was not reasonably practicable to obtain at the time, shows this is not the case.

It is good practice to use the structure set out in this toolkit in the vast majority of cases, if only to show that a particular factor was considered and disregarded. Decision-makers who deviate from the process will require good reasons to do so, which must be carefully recorded.

# 4

## Section 4: Who is the decision-maker and who should be consulted?

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### Key points:

- Best interests assessments are a matter for everyone involved in caring for the person. It should be clearly established, however, who has overall responsibility for making and recording that decision.
  - Family members or “next of kin” do not have a legal right to make decisions on the person’s behalf – unless they have been granted this right specifically as a health and welfare attorney or as a court-appointed deputy. They must, however, be consulted as part of the decision-making process.
  - The person responsible for making the best interests decision must consult with:
    - anyone named by the person as someone to be consulted on such matters;
    - those “engaged in caring for the person or interested in his or her welfare”; and
    - a court-appointed deputy (if there is one).
  - Where there is no one who fits into any of the above categories, an Independent Mental Capacity Advocate (IMCA) must be appointed whenever a decision is required about:
    - providing, withholding or stopping serious medical treatment;
    - whether to move a person into long-term care in hospital or a care home; or
    - whether to move a person into different long-term accommodation.
  - IMCAs may also be instructed in other decisions regarding care reviews or adult safeguarding processes. It can also be helpful, if the service is available, to involve them in other decisions.
  - Where there is disagreement or dispute as to whether the proposed course of action is in the best interests of the person, that cannot be resolved by other means, the Court of Protection remains the ultimate decision-maker and can and should be asked to decide.
- 

### Who is responsible for making best interests decisions?

With the exception of someone with a lasting power of attorney, or a court-appointed deputy, the Mental Capacity Act 2005 (MCA) does not identify a particular individual as having legal responsibility for decision-making. Instead, it focuses on a collaborative approach to decision-making.

Best interests assessments are therefore the responsibility of everyone involved in caring for the person. The approach to decision-making should be multi-disciplinary and seek to involve and hear from all members of the care team who can contribute.

Delays can be caused by no-one taking overall responsibility for decision-making. It is therefore important to establish early on who the “decision-maker” is, and to communicate this to those close to the person and everyone else involved in his or her care.

Where a decision involves the provision of medical treatment, the doctor or other member of healthcare staff responsible for carrying out the particular treatment or procedure is the decision-maker.<sup>13</sup> Where the course of treatment or action being proposed is more likely to involve serious consequences for the person, it will become necessary for the responsible clinician to be the most senior clinician with overall responsibility for the patient’s care.

# 4

This does not mean that the clinician can make their decision in isolation, without consulting with anyone else involved in the care of the person – see below.

## What about family members and “next of kin”?

For practical reasons, people are frequently asked to name their “next of kin” when being admitted to hospital or registering with a general practice. This has led to a great deal of confusion, with many family members – and some healthcare professionals – believing that anyone named as “next of kin” have some legal status to make decisions on behalf of the person.

It is important to be clear early in the process that, being named as “next of kin” on medical records does not grant any legal right for decision-making, and that those close to the person cannot give consent to, or refuse treatment on that person’s behalf unless they have been formally appointed as a health and welfare attorney, or a court-appointed deputy. If the decision relates to life-sustaining treatment, the attorney must have been appointed with additional powers to consent to or refuse life-sustaining treatment (court-appointed deputies cannot be given this power).

It can be helpful to discuss with family members early on what everyone’s respective role is in the decision-making process, and how they should be involved and contribute.

## Who should be involved in decision-making?

The Mental Capacity Act states that the decision-maker must:

*“...take into account, if it is practical and appropriate to consult them, the views of –*

- (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind;*
- (b) anyone engaged in caring for the person or interested in his welfare;*
- (c) any donee of a lasting power of attorney granted by the person; and*
- (d) any deputy appointed for the person by the court, as to what would be in (a)*
- (e) the person’s best interests and, in particular, as to the matters mentioned in subsection (6).”<sup>14</sup>*

## Anyone named by the person as someone to be consulted on the matter

Where the person has named one or more people to be consulted but has not formally appointed them as health and welfare attorney, their views about the person’s best interests should be sought. This could include, for example, someone named in medical records as someone to be involved in decision-making or, where the person is able to express a view currently, anyone named by them when asked.

When making an ADRT, people are sometimes asked to name someone as a “proxy” decision-maker – this is often the case where ADRT templates have been downloaded from an international website where proxy-decision making is more common. This does not mean that that person has been granted decision-making powers. Legally, a proxy decision-maker can only be appointed by granting lasting power of attorney, or if the Court of Protection appoints someone as a deputy. Someone named as a “proxy” in an ADRT should be involved in consultation but does not have decision-making authority and cannot overrule the decision a person has made in their ADRT.



# 4

## Anyone engaged in caring for the person or interested in his welfare

The second category of people identified by the MCA is potentially quite broad and open to interpretation. How extensive it will be depends on what is “practical and appropriate” in the individual circumstances, and on the consequences of the decision being made. It is up to the decision-maker to decide how widely to consult.

For the most part, this will normally include family members – which includes immediate relatives, adoptive families, families of choice, as well as spouses (whether by marriage or civil union), partners, and people with close personal relationships (whether or not these are legally recognised). Where someone has no family, or where it is appropriate to consult more widely, you may wish to consult a wider network of relatives or speak to close friends or others who are part of the person’s wider social circle or community. They may be aware of the person’s views and values or have relevant information to share.

Throughout this toolkit, we use “family and friends” and “those close to the patient” interchangeably. Both should be interpreted in the wider sense of all those close to the person who should be involved and engaged in the best interests decision.

For more significant decisions it is important to ensure that attempts are made to identify all relevant people to be consulted about whether a particular course of action would be in the person’s best interests. This can go beyond immediate family and friends – in some cases, a neighbour or even a colleague may have been more involved in the person’s day-to-day life and have a clearer view of their wishes than immediate family members. Identifying those individuals can be difficult, but you may wish to:

- ask the person, if they are able to express a view, whether there is anyone else they would like to be involved;
- ask those closest to the person whether there are other family members, friends, colleagues, carers or associates who might have information to contribute;
- ask those who have provided information if they are aware of anyone else who might hold a different view to their own – it is important that you hear from them and consider and weigh these as part of your assessment of the person’s best interests; or
- ask other members of the healthcare team who visits the person regularly to assess whether they should be consulted.

This category also covers members of the healthcare team and anyone else involved in caring for the person, including carers, whether paid or unpaid. The views of care staff at all levels can be helpful and relevant in assessing what decision the person would judge to be in his or her best interests – particularly those who have spent a considerable period of time with the person and those close to them.

## Court-appointed deputies

In some cases, the Court of Protection may have appointed a deputy to make ongoing healthcare decisions on behalf of the person. As set out in **Section 2**, where deputies have been authorised to make a particular decision by the court, they are the decision-maker (with the important exception that deputies cannot consent to or refuse life-sustaining treatment).<sup>15</sup>

Where their powers do not cover the decision in question, they must still be specifically consulted as part of the best interests decision.

# 4

## The person themselves

The courts have made clear that the fact that a person lacks capacity does not automatically mean that their views can be excluded or discounted in the decision-making process. The person lacking capacity should participate as fully as is possible in any decision affecting them.

*“...a conclusion that a person lacks decision-making capacity is not an ‘off switch’ for his rights and freedoms. To state the obvious, the wishes, feelings, beliefs and values of people with a mental disability are as important to them as they are to anyone else, and may even be more important. It would be wrong in principle to apply any automatic discount to their point of view.”<sup>16</sup>*

Wherever possible, the person who lacks capacity to make a decision should still be involved in the decision-making process.<sup>17</sup> They may have views on matters affecting the decision or on what outcome would be preferred, however these views may be demonstrated, articulated, or indicated by their actions, behaviour, or responses (whether verbal or non-verbal).

Consulting the person involved may take some time. It is important to allow sufficient time to explain what is happening, why a decision needs to be made, and to hear from the person involved. You may wish to consider:

- using simple language and/or illustrations to help the person understand the decisions and their options;
- asking them about the decision at a time and in a location where the person feels most relaxed and at ease;
- using specialist interpreters or speech and language therapists to aid communication;
- involving trusted relatives or friends, or carers or advocates who may be able to help the person express a wish or to indicate a preference between options; and
- any non-verbal behaviours or responses which might indicate how a person feels about a particular treatment or intervention.

How much weight to be given to the views and feelings expressed by a person who lacks capacity, and how they should be balanced with the other factors to be taken into consideration as part of the decision-making process, is explored in **Section 6**.

### What does “practical and appropriate” mean?

Decision-makers must show that they have thought carefully about who to speak to. If it is practical and appropriate to speak to someone, you must do so and take their views into account. If you do not speak to a particular person, you must be able to explain why you chose not to do so, and the reasons for this should be recorded in the patient’s notes.

What is “practical and appropriate” will vary in different cases, but you must be able to justify a decision not to consult someone. Even in an emergency situation there may still be an opportunity to communicate with or contact those close to the patient.

*“I am not satisfied that it was other than practicable and appropriate to have attempted to contact Mrs Winspear before the DNACPR form was affixed to Carl’s records. Although her willingness to be woken in the small hours was not known to the clinicians at the time, the fact that she had a telephone, had been Carl’s carer from birth, had been in the hospital the previous day and had kept in touch with nursing staff would or should have been known.”<sup>18</sup>*

16 *Wye Valley NHS Trust v Mr B* [2015] EWCOP 60. 11.

17 Mental Capacity Act Code of Practice s.5.21-5.22.

18 *Winspear v City Hospitals Sunderland NHS Foundation Trust* [2015] EWHC 3250 (QB). 58.

# 4

Decision-makers must also not be influenced in their decision about who to consult by a desire to achieve agreement on a particular outcome. It is also important that decision-makers listen to everybody and do not dismiss or discount information because it does not fit with what they have heard from others or their own view, or accept a different point of view uncritically. All of this information should be considered and weighed as part of the best interests decision-making process – which is explored in more detail in **Section 6**.

## How can I do this and respect the patient’s confidentiality?

People who lack capacity are owed the same duties of confidentiality as other patients – although the very nature of the best interests decision-making process requires relevant information to be shared with others to reach a decision.

A decision to share relevant information with others will also involve consideration of whether it is in the person’s best interests to do so. Unless the individual had previously requested that information is not shared with others, it is reasonable to assume that it is in their best interests for relevant information to be shared with those who are able to contribute to the decision-making process.

## When should I involve an Independent Mental Capacity Advocate (IMCA)?

The MCA created the Independent Mental Capacity Advocate (IMCA) service to provide independent safeguards for people who lack capacity and, at the time the decision needs to be made, either have no-one else to support or represent them, or where it would be inappropriate to consult them. The role of the IMCA is to support and represent the person in the decision-making process. Their role is to advocate for the person, not to make the best interests decision itself.

IMCAs are only available to people who:

- lack capacity to make a specific decision about serious medical treatment or long-term accommodation;
- have no family members and/or others who are available and appropriate to support or represent them apart from professionals or paid workers providing care or treatment; and
- have not previously named someone who could help with a decision; and
- have not made a lasting power of attorney.<sup>19</sup>

An IMCA **must** be instructed and consulted for people who fall into the above category when:

- an NHS body is proposing to provide, withhold or stop “serious medical treatment” (defined as treatment where there is a fine balance between benefit and risk; where the choice of treatments is finely balanced; or the proposed treatment is likely to have serious consequences for the patient);<sup>20</sup>
- an NHS body or local authority is proposing to arrange accommodation (or a change in accommodation) in a hospital for 28 days or more; or
- an NHS body or local authority is proposing to arrange accommodation in a care home for more than eight weeks.

<sup>19</sup> Mental Capacity Act Code of Practice, s.10.69.

<sup>20</sup> Mental Capacity Act 2005 (Independent Mental Capacity Advocate) (General) Regulations 2006, regulation 4.

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The only exception to this is in situations where an urgent decision is required.<sup>21</sup>

IMCAs **may** also be appointed in care review processes or adult protection cases involving vulnerable people.<sup>22</sup>

Where a decision is particularly serious or complex, and where the resource is available, there may be benefit in involving an advocate even where there are family members and/or others available and positively engaged in the discussion. An IMCA or another experienced advocate can help with the gathering of information to be taken into account in the best interests assessments, or in identifying others who should be consulted. Some families have also reported finding it helpful to have someone to help them navigate through the process, and to ensure that the person's views and likely wishes are heard.

## **When might it not be appropriate to consult with family and friends?**

Situations where it may not be appropriate to consult with family and friends could include:

- where it is impractical to consult with the family member or friends – e.g. an elderly person whose only surviving relative is an adult child who lives thousands of miles away and rarely maintains contact;
- where the family member or friend does not want to be involved in the decision – e.g. they do not feel they know the person's views well enough, or do not feel able to be participate in the decision required;
- where there are concerns about, or proved incidences of, abuse or coercion by the family member or friends.

The fact that a family disagrees with a proposed course of action is not grounds for concluding that there is no one appropriate who can represent the person's views, and for appointing an IMCA.

## **What role does the Court of Protection play?**

There are some instances where the Court of Protection will be the ultimate decision-maker. For full details of these, please see Section 2 on the court's role in cases of disagreement or dispute.

21 Mental Capacity Act Code of Practice s.10.3.

22 Mental Capacity Act Code of Practice ss.10.59-10.68.

# 5

## Section 5: What should be considered as part of a best interests decision?

### Key points:

- Best interests decisions are not just decisions about the best clinical outcome for the person. You must also consider a person's emotional and welfare interests. The law therefore places great weight on ascertaining the person's past and present wishes, feelings, beliefs and values.
- You should consult with those who know the person and can provide information about their past or present wishes, feelings, beliefs and values in order to assess what the person would have wanted.
- You should avoid speculation or assumptions about what the individual's views might have been in the absence of reliable evidence.
- If there is significant uncertainty or disagreement about the person's wishes, feelings beliefs or values that cannot be resolved, you should seek legal advice as to whether the Court of Protection may need to be involved.

### What counts as wishes, feelings, beliefs and values?

The Mental Capacity Act 2005 (MCA) states that the decision-maker must:

- "...consider, so far as is reasonably ascertainable –*
- (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),*
  - (b) the beliefs and values that would be likely to influence his decision if he had capacity, and*
  - (c) the other factors that he would be likely to consider if he were able to do so."*<sup>23</sup>

The purpose of the best interests test is to consider matters from the person's point of view.<sup>24</sup> The law places great weight, therefore, on ascertaining the person's past and present wishes, feelings, beliefs and values. These categories cover a broad range of information, and you might like to consider the following questions in carrying out your assessment:

- What was the person like before becoming ill?
- What was their job? Did they have any hobbies or interests?
- What did they like or dislike? What parts of their life were particularly important to them?
- Did they ever say or do anything which indicates how they might feel about their current situation?
- Did they ever write anything down which might indicate their views – for example, in e-mails, on social media, or in an advance statement or advance care plan?
- Do they have any religious, spiritual or ethical beliefs that might impact on their view of their current situation?
- Are there any other aspects of the person's personality that might be relevant to understanding what their views might be?

How expansive your consideration of wishes, feelings, beliefs and values is will depend on the nature and consequences of the decision being made. The amount of information that you need to do obtain will vary depending on the individual case. Your aim should be to accumulate enough information to be able to form a sufficiently clear view as to what the person would have wanted for him or herself, had they the capacity to make the decision for themselves.

<sup>23</sup> Mental Capacity Act 2005 s.4(6).

<sup>24</sup> *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67.

# 5

## What does “reasonably ascertainable” mean?

How much you can learn about a person’s past and present views will depend on the circumstances and the time available. “Reasonably ascertainable” means considering all possible information in the time available.<sup>25</sup>

As with making the decision about who to consult, what information is available and ascertainable in an emergency will be very different to what is available in a non-emergency. Even in an emergency there may still be an opportunity to communicate with the person and to contact their family, friends or others who should be consulted.

## How do I ascertain what the person’s wishes, feelings, beliefs and values are?

There are many potential sources of information concerning the individual’s views. How widely you consult and examine will depend on the nature and consequences of the decision being made. Other members of the healthcare team may be able to assist with this process, both by providing information themselves, and by consulting with others close to the patient and bringing all that information together.

As has been made clear throughout this toolkit, best interests decision-making is a process rather than a one-off assessment. In most cases, best interests will be ascertained following a number of discussions, conversations and information gathering rather than by seeking to obtain all of this information all at once.

### The person themselves

Wherever possible, the person who lacks capacity to make a decision should still be involved in the decision-making process.<sup>26</sup> They may have views on matters affecting the decision or on what outcome would be preferred, however they may be demonstrated, articulated, or indicated through their actions, behaviours or responses (whether verbal or non-verbal).

It is extremely important to take all practical steps to assist the person concerned to participate in the process. For more information about how to do that, please see **Section 4**.

### Anything the person wrote down

The MCA highlights the importance of considering any relevant written statements which show how the person might feel about their current situation. This could include any diary entries, letters or emails – but increasingly, might also include any comments or posts on social media. The person’s family might be able to help with access to these.

Other written documents can also be useful – for example, if the person has made an advance statement or advance care plan, or made an ADRT which doesn’t meet the standards required to be valid and applicable. In the latter circumstances, the information contained in it may still help give a clear indication of the person’s wishes for their future medical treatment and care, which can be taken into consideration as part of the best interests assessment.

### Those close to the person

It is a requirement of the Act to consult, if it is practicable and appropriate, with a range of other people who may be able to contribute the type of information required. Those who know the person well will often have valuable information about their wishes, feelings, beliefs and values. They may, for example, be able to recall conversations about the person where they expressed a view which relates to their current circumstances, or share how they responded to similar treatments or interventions in the past.

<sup>25</sup> Mental Capacity Act Code of Practice, s.5.39.

<sup>26</sup> Mental Capacity Act 2005 s.4(4).

# 5

Different people who knew the person well may present their wishes and feelings differently. This may be because they knew the person in different contexts, or because their perception is shaped by their own views. It is important to be able to distinguish the views of the person from the views of family members or others close to them. In some cases, family members may simply not be able to separate their views from the views of the person. In other cases, there may be ulterior motives for the views they express.

Differences of opinion should be explored sensitively. Seeking views from a number of different people and seeking examples or evidence to back up statements or views expressed are good ways of testing the information provided, and ensuring that decisions are informed by the person's own wishes, feelings, beliefs and values – not those of others.

This does not mean that the impact on family members or others is irrelevant altogether – you can consider the effect of a decision on them, to the extent that the person themselves would be likely to do so.

For more complex or distressing decisions, it can be difficult for those close to the patient to articulate all the information they want to face-to-face; in these circumstances it can be useful to offer them the opportunity to provide a written statement to you to be considered as part of the best interests process.

## **What if I'm not sure about what the person's wishes, feelings, beliefs and values are?**

It may not always be possible to identify consistently expressed or reliable wishes and feelings. In these cases, evidence about the person's personality, character or beliefs may help give a clearer indication of what their views might have been, had they been able to express them.

The quality of, and weight to be given to, this information needs to be carefully assessed. Decision-makers must be careful not to speculate or make assumptions about what the individual's views might have been in the absence of reliable evidence.

Where uncertainty about the person's wishes, feelings, beliefs or values persists and cannot be resolved, you should seek legal advice as to whether the Court of Protection may need to be involved.

## **What if someone has never had capacity?**

Where a person has never had capacity, and so has not been able to express capacitous wishes or feelings, a similar process needs to be carried out to gain an accurate picture of the person, including any likes or dislikes, how they appear in day-to-day life, and any non-verbal behaviours or responses that indicate how they feel about something. This information should be considered as part of the best interests assessment.

More difficult is a situation where a person lacks capacity but has never been able to express wishes and feelings of any kind. The issue has not been considered in the courts in relation to adults, but in cases involving young children, the courts have made clear that "the starting point is to consider the matter from the assumed position of the patient" and that "the paramount consideration is best interests".<sup>27</sup>

As is the case in all best interests decisions, you need to be able to show how you reached your decision and the different factors that you took into consideration. The greater the uncertainty about the correct decision, the greater the degree of scrutiny that needs to be applied – including considering

<sup>27</sup> *Kings College NHS Foundation Trust v Hastrup* [2018] EWHC 127 (Fam). 69.

# 5

seeking legal advice or making an application to the Court of Protection. What if someone's present wishes seem different from their previously expressed wishes?

Difficulties arise where a person's previously expressed capacitous wishes or views are different or appear to be in conflict with their current attitude or behaviour – for example, where someone who had previously expressed a wish for treatment to be stopped should they reach a certain stage of their illness now seems to be content with their current situation.

The courts have made clear that the fact that a person appears to be content or happy does not automatically invalidate their previously expressed wishes or provide a clear view as to the course of action to be taken.<sup>28</sup> The emphasis must be on the decision-maker carefully assessing the available evidence and taking all reasonable and appropriate steps to identify what is in the best interests of the person in relation to the particular decision that is required. As is the case in all best interests decisions, you need to be able to show how you reached your decision and the different factors that you took into consideration. The greater the uncertainty about the correct decision, the greater the degree of scrutiny that needs to be applied – including considering seeking legal advice or making an application to the Court of Protection.

## What if what is in someone's best interests involves a more restrictive intervention?

As the MCA makes clear, anyone who lacks the capacity to consent must be cared for in accordance with the "least restrictive" principle (**see Section 1**). There may, however, be some occasions where it will be in someone's best interests to be restrained or deprived of their liberty for a period of time to enable care and treatment to take place. This can include physical or chemical restraints, locked wards, or any measure which restricts the person's ability to make a decision about whether to stay somewhere.

These acts are covered by the MCA, as long as a person has a reasonable belief that it is necessary to carry out a restrictive intervention to prevent harm to the person, and that it is a proportionate response to the likelihood and seriousness of that harm.<sup>29</sup>

If the restrictions reach a certain threshold, however, they must be legally authorised. In England and Wales this is done via the Deprivation of Liberty Safeguards (DoLS), which will soon be replaced with the Liberty Protection Safeguards (LPS).<sup>30</sup>

If you are caring for a person who is, or who may need to be, deprived of their liberty, you should consult our dedicated guidance on DoLS, which is available at [www.bma.org.uk/ethics](http://www.bma.org.uk/ethics). Updates on the introduction of the LPS will also be provided here.

28 *Briggs v Briggs* [2016] EWCOP 53. 52.

29 Mental Capacity Act 2005 s.6.

30 Mental Capacity (Amendment) Act 2019.



# 6

## Section 6: How do I use the information?

### Key points:

- All the information and evidence gathered about the person’s wishes, feelings, beliefs and values, and the person’s current experiences – whether positive or negative – needs to be carefully assessed in relation to the clinical options and their associated risks and benefits.
- The law is not clear about what weight should be given to a person’s wishes, feelings, beliefs and values in relation to the other information necessary for a best interests decision – but the reliably ascertained views of a person should be given substantial weight.
- Our guidance is that where it is clear what decision the person would have taken had they had capacity, this will generally give the answer as to what is in their best interests. If you depart from that, you should be able to justify why you did so.
- A balance sheet approach can help to ensure that all relevant factors have been carefully considered and to demonstrate how and why the decision has been reached.
- This exercise is not a numerical one and it is the weight of the arguments, rather than the number on each side, which assists in identifying what is in the person’s best interests.

### How much weight should be given to the person’s wishes?

#### Previously expressed wishes, feelings, beliefs and values

All the information and evidence gathered about the person’s wishes, feelings, beliefs and values, and the person’s current experiences – whether positive or negative – needs to be carefully assessed in relation to the clinical options and their associated risks and benefits.

The Mental Capacity Act 2005 (MCA) does not specify what weight should be given to a person’s wishes, or set out a hierarchy of relevant factors. From case law, it is clear that a person’s wishes will be important but not necessarily determinative.<sup>31</sup>

*“The purpose of the best interests test is to consider matters from the patient’s point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient’s wishes are... But insofar as it is possible to ascertain the patient’s wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.”<sup>32</sup>*

More recent case law, in the context of decisions about life-sustaining treatment, has emphasised that where it is clear what decision the person would have taken had they had capacity, this will almost always give the answer as to what is in their best interests.<sup>33</sup> Where it is possible to clearly identify the course of action that the person would have taken had they had capacity, then any divergence from that would need to be reasonable, justifiable, and clearly recorded.

31 39 Essex Chambers (April 2019) *A Brief Guide to Carrying Out Best Interests Assessments*. Para.17.

32 *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67. 39.

33 *Salford Royal NHS Foundation Trust v Mrs P* [2017] EWCOP 23.

# 6

## Currently expressed wishes, feelings, beliefs and values

As we have noted above in Section 4, wherever possible, the person who lacks capacity to make a decision should still be involved in the decision-making process.<sup>34</sup>

Although a person who lacks capacity should participate as fully as is possible in any decision affecting them, the weight which should be given to their wishes, feeling, beliefs and values will vary depending on the circumstances of each case. The courts have stated that:

*"...once incapacity is established so that a best interests decision must be made, there is no theoretical limit to the weight or lack of weight that should be given to the person's wishes, feelings, beliefs and values. In some cases, the conclusion will be that little weight or no weight can be given; in others, very significant weight will be due..."*<sup>35</sup>

## How do I balance and weigh different factors?

In some cases it will be clear which option on the table will be in the best interests of the person. In others, there may be other more complex competing factors which need to be weighed against one another. In these cases, it may be useful to use a balance sheet approach to decision-making.

The balance sheet approach involves setting out the potential risks and benefits of each option side-by-side. This is not a purely numerical exercise: it is not the case that the side with the most factors on it will be determinative. It is the weight of the arguments that is important. Each factor must be appropriately weighed, and the reasons for weighing them in this way provided. Simply listing them as pros and cons without attributing any importance to them will not be helpful.<sup>36</sup>

In carrying out this exercise, it may become clear that although there are many risks and benefits, in some cases, one risk or benefit may be of overriding importance, and so have a decisive influence. These are often called "factors of magnetic importance".<sup>37</sup>

As has been emphasised above, it is not just the decision reached that is important, but the process through which that decision was made. For this reason it is crucial to set out and record the reasons why the decision was reached, and how.

34 Mental Capacity Act Code of Practice s.5.21-5.22.

35 *Wye Valley NHS Trust v B* [2015] EW COP 60. 10.

36 *Re F (A Child) (International Relocation Case)* [2015] EWCA Civ 882. 52.

37 *Crossley v Crossley* [2007] EWCA Civ 1491. 15.

You might find it helpful to use the template below as a starting point.

Patient details	
Decision-maker	
Decision required	
Evidence that the person lacks the capacity in relation to the decision in question – <i>including a summary of steps taken to maximise decision-making capacity</i>	
Clinical and diagnostic assessment	
Contributors to the best interests process <i>Is there anyone else who should be involved?</i>	
Summary of person's views, wishes and feelings	
Currently expressed views:	Previously expressed views:
Other relevant information (e.g. any additional information about the person's interests, life, relationships with others)	
Options	
Option 1	
Benefits to the person of enacting the decision:	Burdens or risks to the person of enacting the decision:
Option 2	
Benefits to the person of enacting the decision:	Burdens or risks to the person of enacting the decision:
Option 3	
Benefits to the person of enacting the decision:	Burdens or risks to the person of enacting the decision:
Add more options if necessary...	
Decision reached – including reasons for the decision and how it was reached	

# 7

## Section 7: Best interests meetings

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### Key points:

- Best interests meetings are not required by the Mental Capacity Act 2005 (MCA) but are a good way of making important healthcare decisions for adults who lack capacity, and to demonstrate that a best interests decision has been properly considered.
  - Best interests meetings are one part of the process of decision-making and should not be seen as a single, determinative event.
  - Members of the healthcare team and those close to the person should both be equally involved in the best interests meetings, allowing sufficient time for everyone involved to express what they want to contribute to the meeting.
  - Careful planning, preparation and gathering of information can help maximise the effectiveness of best interests meetings. This should include consideration of where and when meetings should be held and who should be involved, and identifying the issue to be discussed.
  - A detailed note of the meeting should be circulated to all those in attendance to check its accuracy before it is finalised. It may also be helpful to make a digital recording to share with those present.
- 

Best interests meetings are not a requirement of the MCA. They can be helpful, however, for ensuring that a best interests decision is properly considered; that all relevant people are involved in the discussion; and that the correct process has been followed. They can be particularly helpful for decisions that are complex or are likely to have serious consequences for the person.

As has been made clear throughout this toolkit, best interests decision-making is a process. As such, best interests meetings should be viewed as one part of this process, rather than a single determinative event. Discussions about best interests are likely to have started long before this point, even if not explicitly framed as such, and more than one best interests meeting may be needed before a decision is made.

A best interests meeting can be convened especially in a particular case, or it can form part of a wider multi-disciplinary meeting or case review.

### What is the purpose of best interests meetings?

The main purpose of best interests meetings will be to collect and discuss relevant information to enable a decision to be made about what course of action is in the best interests of a person. In accordance with the MCA, the focus of the best interests meeting must be the person who lacks capacity and on reaching the decision that is right for them.

As noted above, best interests decision-making is a process, and any meetings will be part of that. Accordingly, it will be important at the outset of any meeting to state what decision is being considered, when it needs to be made, and who the decision-maker is.



### Who should be involved?

It is the responsibility of the clinician in charge of the patient's care to initiate best interests meetings, but they can also be requested by a family member or another member of the healthcare team.

They should involve, as far as possible:

- **the person:** the person may not be willing or able to attend the meeting themselves, but it is important that any views they are able to express are represented and considered appropriately;
- **those close to the person:** the person's family or friends, any court-appointed deputies, anyone who has lasting power of attorney, or, where appropriate, an IMCA. It can also be helpful to involve anyone those close to the patient would like to have at the meeting to provide support or advocacy;
- **the healthcare team:** those involved in caring for the patient as part of the multi-disciplinary team (MDT); and
- **administrative staff:** anyone else who should be involved in the efficient running of the meeting.

It is important to make sure that numbers are manageable, and that in particular, neither the person's family nor the clinical team feel intimidated, outnumbered, or overwhelmed. Careful planning ahead of time as to attendees, timings, and venue can all help with this.

### How should they be run?

Ahead of the meeting, someone should be designated to chair or facilitate. In some cases, this may be the decision-maker themselves, but in other cases it may be deemed more appropriate to have some separation between the decision-maker and whoever is chairing or facilitating the meeting.

It is important to allow enough time for non-clinicians to understand the relevant clinical aspects of the decision and the likely consequences of any decision for the person, and to ask questions. Similarly, there must also be enough time for family members and others close to the person to inform the clinical team about the person and their wishes, feelings, beliefs and values.

It can take time for clinicians to consider that information fully and to form a holistic picture of the person. Family members and others close to the patient may wish, or find it easier, to provide that information in writing ahead of the meeting.

Local areas may have their own procedures and processes for planning and running these meetings, but generally they should address the following:

- Who is the decision-maker?
- Is there a time and decision-specific assessment of capacity in relation to the person?
- What support has been offered to the person to enable them to make their own decision?
- Is the nature of the decision clear? Do all those attending the meeting understand the nature of the decision being made, the available options, their likely risks, benefits and harms, and the significance of these for the individual?
- Have all reasonable steps been taken to ensure that the person in question can participate as far as possible in the decision?
- Has consideration been given to the time and place of the meeting? Have reasonable steps been taken to ensure the supported participation of the individual and those close to them?
- Have all relevant individuals been invited or given an opportunity to provide information relevant to the decision?
- Where appropriate, has an IMCA been appointed and are they in attendance?
- Are all those in attendance familiar with the MCA checklist as set out in s.4 of the Act? Have all relevant parts of this checklist been properly addressed as part of the decision-making process? (See also Section 3 of this toolkit).



- Have you considered whether a “balance sheet” approach is appropriate in this case?
- Do you have all the relevant information necessary to make the decision required?
- Have you sought and considered information about the person as an individual and his or her likely wishes?
- Is an accurate record of the meeting being taken?

It can also be helpful to discuss next steps for any decisions reached at the meeting:

- What are the decisions that were made?
- Who is going to implement them and how?
- What is the timeline for implementation?
- If it was not possible to make decisions at this meeting, what is going to happen next? Who is responsible for the next steps and what is the timeline? This should include setting a date for review of this decision, if necessary.

In some circumstances, and where everyone is happy with the arrangement, it may also be helpful to make a digital recording of the best interests meeting. This allows both healthcare staff and those close to the person to listen again to the information in their own time and enables those who could not attend to hear first-hand what was said. It also ensures that a full and accurate record of the meeting is available to all parties.

### **What should happen afterwards?**

A detailed record should be kept of all best interests meetings, summarising the information exchanged and clearly documenting the decisions reached. It is good practice for notes to be shared with everyone who was at the meeting, allowing them to check for accuracy before they are finalised.

# 8

## Section 8: Recording the decision and keeping it under review

### Key points:

- You should keep an accurate record about all best interests decisions made, including:
  - the decision reached;
  - the reasons for reaching the decision;
  - who was consulted to help work out best interests; and
  - what particular factors were taken into account.
- Capacity is decision-specific: it focuses on the specific decision that needs to be made at the time the decision is required. The assessment of capacity is not a single one-off event, but one that needs to be regularly assessed in relation to each decision required.
- What is in a person's best interests may also change over time. This means that even where similar actions need to be taken repeatedly in connection with the person's care or treatment, the person's best interests should be regularly reviewed.

### How should I record a best interests decision?

As per General Medical Council (GMC) guidance, doctors should keep an accurate record about the person's treatment and care, and of who was consulted in relation to decisions about that.<sup>38</sup> Additionally, the MCA Code of Practice also requires that a detailed record should be kept of all best interests decisions made and how they were reached.<sup>39</sup>

In addition to the decision itself, the record should include:

- how the decision about best interests was reached;
- what the reasons for reaching the decision were;
- who was consulted to help work out best interests; and
- what particular factors were taken into account.

Where a balance sheet exercise was carried out, this should also be included as part of the notes.

This record should remain on the person's medical notes and transfer with them to other care settings, if necessary.

The healthcare professional responsible for a best interests decision is also responsible for ensuring that the decision is communicated effectively to other health and social care professionals involved in caring for the patient.

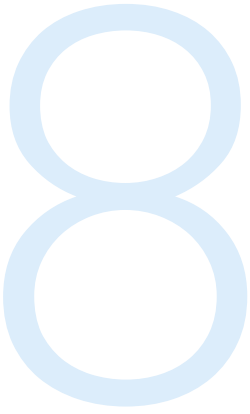
### Keeping best interests decisions under review

As noted at the outset of this toolkit, capacity is decision-specific: it focuses on the specific decision that needs to be made at the time the decision is required. It is not a single one-off event, but one that needs to be regularly assessed in relation to each decision required. For this reason, it is important for capacity to be regularly reviewed.

Similarly, what is in a person's best interests may change over time. This means that even where similar actions need to be taken repeatedly in connection with the person's care or treatment, the person's best interests should also be regularly reviewed.

<sup>38</sup> General Medical Council (2010) *Treatment and care towards the end of life: good practice in decision making*. GMC: London. Para 75.

<sup>39</sup> Mental Capacity Act Code of Practice s.5.15.



Neither the Mental Capacity Act 2005 (MCA) nor the MCA Code of Practice specify precise time periods in which reviews of capacity or best interests should take place. Reviews should generally take place:

- whenever a care plan is being developed or reviewed;
- where a person’s condition changes materially;
- at other relevant stages of the care planning process; and
- as particular decisions need to be made.

It is important to remember that continuing treatment or interventions “by default” without consideration of a person’s best interests is contrary to your legal duties under the MCA.



# 9

## Section 9: Disputes

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### Key points:

- Where there is disagreement or dispute, this should be tackled and resolved as soon as possible.
  - Various formal and informal options exist to help resolve disputes or disagreement, including, for example, the use of a second opinion, the involvement of an Independent Mental Capacity Advocate (IMCA), the involvement of clinical ethics support services (such as clinical ethics committees) or the use of medical mediation services.
  - Where dispute or disagreement persists, legal advice should be sought and, if deemed necessary, an application to the Court of Protection should be made.
- 

In most cases, decisions relating to an incapacitated adult's best interests are made following agreement between the clinical team and those close to the patient. There will be times however where there is disagreement as to what is in the person's best interests. It is in everyone's interest – not least the patient's – to try and resolve these as soon as possible, with minimal stress and cost, and before they become more serious and entrenched.

Disagreements can arise in various ways: within the treating team, within a family, or between the treating team and those close to the patient. It is important to note that in the event of a dispute, the Mental Capacity Act 2005 (MCA) does not give precedence either to healthcare professionals or to the person's family.

Many disputes or disagreements can either be avoided, or settled rapidly, with good communication. Where a dispute or disagreement arises, it can be helpful to explore them through the following formal and informal options: further discussion with the person and family and others close to them about the options for care and treatment;

- inviting a colleague, independent of the treating team, to examine the patient and meet with the family to offer a second opinion;
- if the resource is available, by involving an IMCA to attend meetings or to be involved in discussions – some families have reported finding this helpful, even though it is not a requirement;
- arranging a case conference or meeting to discuss matters in more detail;
- seeking the involvement of a local clinical ethics support service, such as a clinical ethics committee (CECs);
- where a decision is not needed urgently, allowing family members more time to consider the available options; or
- using a medical mediation service.

Family members and others close to the patient should be informed of the options available to them if they disagree with a decision, and provided with clear information about the process to be followed and any support that might be available to them.

If these options fail to resolve the issue, legal advice should be sought to determine whether an application to the Court of Protection is needed.

# 10

## Section 10: Best interests and life-sustaining treatment

### Key points:

- Anyone deciding whether or not life-sustaining treatment is in the best interests of someone who lacks capacity must not be motivated by a desire to bring about the person's death.
- There is a strong presumption that it is in a person's best interests to receive life-sustaining treatment, and decision-makers must always start from this premise.
- In some circumstances, however, this presumption will be rebutted by evidence that it will not be in the best interests of the person to receive, or continue to receive, life-sustaining treatment.
- Decisions about best interests in relation to life-sustaining treatment for a person who is not imminently dying should follow the same process as all best interests decisions. However, due to the serious consequences for the person of a decision not to provide life-sustaining treatment, such a process should be more extensive and rigorous than for other more straightforward decisions.

### Who is the decision-maker in decisions about life-sustaining treatment?

As set out in Section 2, there are various ways in which decisions can be taken for or in relation to persons who lack capacity, and it is worth restating them here in the specific context of life-sustaining treatment.

- If the person has made a valid and applicable advance decision to refuse treatment (ADRT), that applies in the person's clinical situation, the person has already decided to decline a certain treatment, and that decision must be respected.
- If the person has made a lasting power of attorney (LPA) appointing a health and welfare attorney, with the power to consent to, or refuse, life-sustaining treatment, and the LPA has been registered with the Office of the Public Guardian, the LPA is the decision-maker. LPAs must follow the principles of the Mental Capacity Act 2005 (MCA) when making decisions and act in the best interests of the person.
- When a decision about life-sustaining treatment is needed and the person has neither an ADRT nor an LPA, it must be made by the clinical team on the person's behalf, based on his or her best interests. Where a person has nobody to represent them or no one who it is appropriate to consult, an IMCA must be instructed.
- In cases where there is disagreement about the person's best interests, or the decision is finely balanced, the Court of Protection is the ultimate decision-maker and should be asked to decide.

It is important to note that a court-appointed deputy does not have, and cannot receive, the power to refuse consent to the carrying out or continuation of life-sustaining treatment.<sup>40</sup>

<sup>40</sup> Mental Capacity Act 2005 s.20(5).

# 10

## What additional considerations apply to best interests decisions about life-sustaining treatment?

Additional considerations apply to decisions about working out a person's best interests in relation to life-sustaining treatment. The MCA states that in making a best interests decision to not provide, or stop providing life-sustaining treatment, the decision-maker must not be motivated by a desire to bring about the person's death. Many family members or others may use expressions such as "he would rather be dead" in describing what they think the person would want; this does not equate to a desire to bring about the person's death and should not be interpreted as such.

There is a strong legal presumption in favour of prolonging life, and decision-makers must start from this premise. This presumption can be rebutted, however, where:

- there is clear evidence that the person would not want the treatment in question in the circumstances that have arisen;
- the treatment itself would be overly burdensome for the person – in relation to what is known about the person's wishes for care and treatment; or
- there is no prospect that the treatment would return the person to a quality of life that would be acceptable to them. It is crucial to emphasise that quality of life must be viewed through the lens of what the person would view as worthwhile, not what the healthcare team or family members might view as worthwhile.

In these cases, a doctor and those close to the patient may well reach the conclusion that it is not in the best interests of the person to continue treatment – even where that may result in the person's death. It is important to note that the decision being reached here is whether it is in a person's best interests to receive life-sustaining treatment, not whether it is in their best interests to be dead or for whether it is in their best interests for treatment to be withdrawn, and decision-makers should be careful to frame the question accordingly.

This decision must be reached, as with all other best interests decisions, following careful consideration and assessment of the person's wishes, feelings, beliefs and values. Due to the serious consequences of a decision not to provide life-sustaining treatment for a person who could, with it, potentially live for a long time, it is likely that an extensive and rigorous consultation and assessment process would be required.

As set out in **Section 8**, what is in a person's best interests may change over time. This means that any decision to provide life-sustaining treatment should be kept under review, to ensure that it continues to be in their best interests. Treatment should not continue to be provided "by default" simply because it was initiated.

We have separate, detailed guidance about the process to be followed when a decision is required about clinically-assisted nutrition and hydration (CANH) which you can download from [www.bma.org.uk/CANH](http://www.bma.org.uk/CANH).

# 11

## Section 11: Useful resources

### BMA guidance

Available to download at [www.bma.org.uk/ethics](http://www.bma.org.uk/ethics)

**Mental Capacity Act Toolkit**

**Consent and Refusal Toolkit**

**Children and Young People Toolkit**

**Adult Safeguarding Ethics Toolkit**

**Deprivation of Liberty Safeguards**

**Decisions about clinically-assisted nutrition and hydration and adults who lack the capacity to consent: Guidance for decision-making in England and Wales** – [www.bma.org.uk/CANH](http://www.bma.org.uk/CANH)

### External links

**Mental Capacity Act 2005** – [www.legislation.gov.uk/ukpga/2005/9/contents](http://www.legislation.gov.uk/ukpga/2005/9/contents)

**Mental Capacity Act Code of Practice** – [assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/497253/Mental-capacity-act-code-of-practice.pdf](http://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf)

**Court of Protection** – [www.gov.uk/courts-tribunals/court-of-protection](http://www.gov.uk/courts-tribunals/court-of-protection)

**Office of the Public Guardian** – [www.gov.uk/government/organisations/office-of-the-public-guardian](http://www.gov.uk/government/organisations/office-of-the-public-guardian)

**Social Care Institute for Excellence**: [www.scie.org.uk/mca](http://www.scie.org.uk/mca)

**39 Essex Chambers** – *A brief guide to carrying out best interests assessments.* This resource is regularly updated and can be found at: [www.39essex.com/resources-and-training/mental-capacity-law/](http://www.39essex.com/resources-and-training/mental-capacity-law/)

**BABEL** (Balancing best interests in healthcare ethics and law) – the interdisciplinary BABEL project explores healthcare decisions for individuals who are unable to make decisions for themselves, with a focus on the nature, purpose, and operation of the best interests standard in decision-making: [www.bristol.ac.uk/BABEL](http://www.bristol.ac.uk/BABEL)

**NICE** guidance for decision-making and mental capacity (2018) – [www.nice.org.uk/guidance/ng108](http://www.nice.org.uk/guidance/ng108)

**GMC** guidance on mental capacity – [www.gmc-uk.org/ethical-guidance/ethical-hub/mental-capacity](http://www.gmc-uk.org/ethical-guidance/ethical-hub/mental-capacity)



**BMA**

British Medical Association, BMA House,  
Tavistock Square, London WC1H 9JP  
[bma.org.uk](http://bma.org.uk)

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